Your
charity
newsletter

CROSSED GRAIN

August 2025
Issue 127

Thank you for helping thousands get diagnosed

This Coeliac Awareness Month, we asked the public to stop and consider a simple yet powerful question: "Is it coeliac disease?"

Thanks to your support, that question reached thousands of people who went on to take our free online self-assessment and begin their journey towards a diagnosis. That's 7,600 lives changed, and it's all thanks to you.

Your generosity and passion didn't stop there. Many of you stepped forward to share your own diagnosis stories, bravely opening up to help others recognise the signs and seek help.

Olympic champion speaks out

One of these key voices was Olympic champion Rebecca Adlington OBE, who shared her life changing diagnosis in October 2024, at age 35. Rebecca's story is a powerful reminder of how coeliac disease can go unrecognised for years. She said:

"I suffered with stomach pain, fatigue, mouth ulcers, bloating, and constantly felt run down or ill. The tiredness affected both my personal and professional life as I didn't feel as productive or have enough energy like other people. I also experienced two miscarriages and whilst my doctor couldn't pinpoint the cause, this and my stomach pain ultimately led to me being tested for coeliac disease and subsequently diagnosed."

Thanks to your support, Rebecca - like so many others found answers, relief, and a supportive community.

"Since removing gluten, I feel significantly better. My mood, my energy - everything is better. I am not in pain anymore. I had lots of people recommend Coeliac UK to me when I announced my diagnosis on social media. I found their support and information so helpful when adjusting to living on a strict gluten free diet."

Rebecca Adlington, OBE

Olympic gold medallist Rebecca Adlington talks about her experience of coeliac disease

Rebecca Adlington: After my miscarriages, I was diagnosed with coeliac disease. It's changed everything

REBECCA ADLINGTON
Double Olympic gold medallist
whereas, actually, it's more

Rebecca's message to others mirrors what your support makes possible every day:

"If you are experiencing ongoing symptoms or issues like I had, just ask the doctor for a test. I never even thought I might have coeliac disease, but I wish I had asked my doctors to test me sooner."

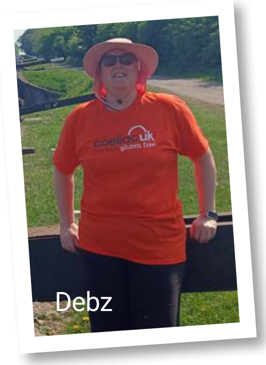
Thanks to you, more people are asking the right questions, getting tested, and finally getting the help they need. Thank you for raising vital awareness, inspiring powerful stories, and empowering others to seek life changing answers.

Is it coeliac disease? Our online self-assessment is always available on our website. So if you know anyone who is experiencing unexplained symptoms, please direct them to: **isitcoeliacdisease.org.uk** or **scan the QR code.**

Having fun raising awareness

More than 100 big hearted supporters took part in our new 64 Challenge in May, raising over £17,000 and putting the spotlight on the issue of low diagnosis rates of coeliac disease.

The challenge highlights how 64% of people with coeliac disease - an estimated 500,000 people in the UK - don't know they have it and suffer in silence. The 64 Challenge was a huge success, thanks to amazing supporters, who found a whole host of ways to fundraise their way.



Debz from Somerset smashed her £640 target and raised a phenomenal £728 walking with friends. Debz was diagnosed with coeliac disease after retiring recently.

"For me, adapting psychologically and socially has been the biggest challenge. I was grateful for the support offered through the charity's **Member2Member** programme. It linked me up with a like-minded lady called Meriel."

"Being able to talk with a kindred spirit who understands how I feel about the challenges of eating out, or at people's homes - where I don't want to feel like I'm a nuisance - has been a major help to me." continues Debz.

"I already feel hugely better, which is why I wanted to give back to the charity. It's helped me so much this year. I took on the challenge to walk with 64 different friends and family to embrace the thing I cannot change, and because I want everyone suffering with undiagnosed coeliac disease to receive a diagnosis. The 64 theme has certainly helped me explain the importance of raising awareness, on a walk or two!"

Caroline who works at Genius Foods, completed 64 sit ups and 64 star jumps every day (and often in fancy dress) for the whole of May!

Marking his 64th birthday, **Huw**, who was diagnosed with coeliac disease in his 20s, walked the Wales Coastal Path in not one, but two, 64km walking challenges.

All this activity follows hot on the heels of 18 amazing supporters who raised £27,500 running the London Marathon in April. We couldn't offer vital support to others without you, thank you!

Juliette (pictured right) with her two daughters at the London Marathon, where she ran for Coeliac UK, commented:

"Throughout the past eight years and from 'Day 1' of finding out that both my daughters have coeliac disease, we've benefited from the charity in so many ways.

Hannah and Sophie are now 14 and 16 years old and this year I took on the challenge of running the London Marathon. The charity has been with us every step of the way, offering practical help and emotional support when we need it most.

If you're thinking of taking on a challenge – please do. Families like ours truly benefit and your support makes a real difference."

Cost of Living campaign reaches number 10

Since releasing our first report on the high cost and poor availability of gluten free food, you've helped us lead the fight for change.

Together, we've urged food manufacturers, retailers, and policymakers to make gluten free options more affordable. And thanks to your voice, prescriptions were reinstated in Sheffield, West Kent, North Central London and South West London.

These wins were only possible because of you, our incredible community. But challenges remain. Across the UK, access to gluten free prescriptions now depends on where you live, creating an unfair postcode lottery that puts lower income families at even greater risk of poor health outcomes.

That's why we launched a petition in November 2024 to safeguard gluten free prescriptions. Over 22,000 of you added your name and this captured the attention of decision makers.

And on 19 March, your support helped power a major day of action in Westminster. Together with patients, healthcare professionals, and MPs, we marched to 10 Downing Street, rallied for change, and hosted a powerful reception in the House of Lords - all to make it clear: **gluten free prescriptions are a medical necessity, not a luxury.**

Your voice helped drive momentum in Parliament too, with supportive MPs raising the issue and keeping pressure on the Government to fix this broken system.

Positive results from our second cost report come as we partner with retailers. A recent trial across 300+ Aldi stores helped to improve access to gluten free food and we look forward to announcing more as our discussions continue.

Your support means we can continue fighting for a fairer future - one where everyone with coeliac disease has access to the affordable gluten free staples they need to stay healthy, no matter where they live.

To find out more about our Cost of Living campaign visit: **coeliac.org.uk/availability**

You're helping us reach more people!

Our team of volunteers and **Member2Member** programme is growing. Last year, we trained 43 new volunteers and we're now looking to recruit more. So, if you want to help support people with coeliac disease as a Member2Member mentor or in any of our other volunteering roles please get in touch.

Register your interest today at: coeliac.org.uk/be-a-volunteer

Making life-changing research possible

RESEARCH APPEAL 2025

Research has always been at the heart of Coeliac UK - and thanks to the incredible generosity of this community, over £50,000 has been raised this year to support new groundbreaking studies.

Coeliac UK has now launched a new Research Call, inviting proposals focused on improving the lives of people with coeliac disease. For the first time, we are offering uncapped grants - meaning applicants can request any amount of funding, guided by the research needed rather than budget limitations This is an extraordinary opportunity to unlock more answers that could transform diagnosis, treatment, and support for everyone affected by coeliac disease.

Thank you so much for being part of this journey.

Find out more about our research projects at coeliac.org.uk/current-research

Research spotlight on ataxia

Here we focus on a promising project, which hopes to improve the diagnosis and management of gluten ataxia. It's led by Professor Marios Hadjivassiliou, Director of the Sheffield Ataxia Centre - one of just two national ataxia centres in the UK, that cares for over 2,500 patients. It's cofunded with Ataxia UK, the Sheffield Hospitals Charity Trust and the Greaves and Withey Foundation.

Professor Marios Hadjivassiliou

What is gluten ataxia?

Gluten ataxia is a neurological disorder, triggered by gluten consumption. Damage to the cerebellum in the brain causes a loss of coordination, poor balance, slurring of speech and a tendency to fall. Left untreated, it can even lead to wheelchair dependency. If it's detected early, and the patient follows a strict gluten free diet, the condition can be stopped from progressing. But late diagnosis can cause permanent neurological disability and diagnosis is difficult.

What does the project hope to achieve?

This research aims to establish a diagnostic pathway for gluten ataxia, so more people can be diagnosed earlier. Researchers have previously identified that certain antibodies, tissue transglutaminase 6 (tTG6) and antigliadin, are present in blood samples of gluten ataxia patients.

As part of the study, patients who have had other types of ataxias ruled out, will have their blood samples tested for gluten ataxia. If tTG6 and antigliadin antibodies are present, patients will undergo a gut biopsy and brain scan as part of the diagnosis pathway. If they're diagnosed with gluten ataxia, they'll be advised on how to adopt a strict gluten free diet. After one year, the patient will be assessed to see what effect the diet has had. This will allow researchers to show how avoiding gluten can stop damage to the nervous system.

For more info on neurological conditions linked to coeliac disease, please visit:
coeliac.org.uk/neurological-conditions

Gifts in Wills could create a future free from coeliac disease

We're always humbled to learn about amazing supporters who leave a gift to Coeliac UK in their Will, because these special gifts are vital to the charity. They often provide around a fifth of our income.

Did you know, as a Coeliac UK supporter, you can write or update your Will for free?

After making sure your family and friends are cared for, a gift will help deliver our support services and campaigns including:

- **Funding research that ultimately paves the way for a cure.**
- **Helping volunteers deliver support locally.**
- **Campaigning for more affordable gluten free food.**
- **Supporting children with coeliac disease at school.**

We remain the largest charity funder of research into coeliac disease in the UK. Since 2005, we have committed around £3.5 million for research projects aimed at finding the answers we need, so one day no one's life will be limited by gluten.

Write your Will for free

Whether you choose to write or update your Will in person, online or over the phone, we can help you do it quickly, easily and for free, with specialist support from our expert partners.

The National Free Wills Network comprises more than 800 Gold Standard solicitors across the UK and is ideal for anyone who would like to make a face to face appointment with a friendly local expert to write or update their Will.

Make time to leave a lasting legacy

If you'd like to request an information pack about leaving a gift in your Will, or perhaps you'd like to find out about setting up a memorial fund for a loved one, please contact Caroline Norris at **caroline.norris@coeliac.org.uk** or visit **coeliac.org.uk/wills**

Thanks to legacies, people like Elizabeth and her family can look forward to a world without coeliac disease – because we know it's possible.

"The charity is very close to my heart. Coeliac disease plays a huge part in my family as it's shared in over four generations, and right now, 12 members of my family, from age 67, which is myself, down to my two year old great niece have coeliac disease."

Elizabeth and her granddaughter Nell, 16, who both have coeliac disease

Coeliac UK nominated for a Nationwide colleague grant

We're so grateful to amazing Coeliac UK member, Laura, whose workplace grant will help fund a new product. Thanks to Laura's nomination to her employer, Nationwide Building Society, we;ve recieved a grant of £9,430 which will help update our gluten free budget meal planner.

It's been downloaded more than 70,000 times since it was launched in 2018, so the grant will continue to help thousands of people. The new look planner will be released later this year, complete with new recipes.

Could your company get involved?

If you're linked to a company who might be interested in supporting Coeliac UK, our partnership with Work for Good – a digitised fundraising platform – makes it easy for companies to donate.

work for good.

To find out more visit: **workforgood.co.uk/charities/coeliac-uk**

Don't miss your chance to WIN BIG

Enter the Summer Raffle and you'll be helping support everyone with coeliac disease. Entering is easy and it costs just £1 per ticket.

"Summer's a busy time for our Helpline and every week our team of dietitians provide hundreds of people with support over the phone and online.

When you play the raffle, you are helping to ensure people get the information and guidance they need, when they need it most, whether they're on holiday, staying in hospital, starting a new school or out shopping for gluten free food. Your support means that we can be there for everyone and help keep the community safe and informed. Thank you." **Naomi**

'Hundreds of people contact us every week for expert information. Your support means that our dedicated team can be here for them.'

Naomi
Coeliac UK Dietitian

Where would £5,000 take you?

Sue from Southampton was the lucky winner of the whopping top prize in our Spring Raffle. Sue has supported the raffle since 2018, soon after being diagnosed with coeliac disease:

"It couldn't have come at a better time. I'm newly retired and next week I'm flying off to Washington DC for a wedding. Even better, we'll be celebrating my husband's 70th birthday when we get back, so a holiday with him and my son - and their golf clubs - will be just the ticket."

Buy your ticket today!

Visit **coeliac.org.uk/raffle** or **scan the QR code** to play today!
Or call the raffle hotline on **01628 511 708** to enter.

Registered with FUNDRAISING REGULATOR

Coeliac UK, Artisan, Hillbottom Road, High Wycombe,
Buckinghamshire, HP12 4HJ

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Get in touch - we always love to hear from you, so if you have any feedback or ideas for the next edition of Crossed Grain email us at **publications@coeliac.org.uk**. You can contact us via email **fundraising@coeliac.org.uk**, or by phone between 10am-4pm on weekdays.

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